

**GOVERNOR'S ADVISORY COUNCIL FOR EXCEPTIONAL CITIZENS (GACEC)  
GENERAL MEMBERSHIP MEETING**

*7:00P.M., January 15, 2019*

**George V. Massey Station, Second Floor Conference Room  
516 West Loockerman Street, Dover, DE**

**MINUTES**

**MEMBERS PRESENT:** Susan Campbell, Cathy Cowin, Bill Doolittle, Karen Eller, Ann Fisher, Terri Hancharick, Robert Overmiller, Jennifer Pulcinella, and Laura Waterland.

**OTHERS PRESENT: Guests:** Stacy Watkins/Division of Developmental Disabilities Services; Kim Krzaznowski, Department of Education Office of Early Learning; Christine Stoops, Parents as Teachers; Helene Diskau, Child Development Watch.

**Staff present:** Kathie Cherry, Office Manager and Sybil Baker, Administrative Coordinator.

**MEMBERS ABSENT:** Dafne Carnright (LOA), Al Cavalier (LOA), Nancy Cordrey, Tika Hartsock, Emmanuel Jenkins, Thomas Keeton, Danna Levy, Mary Ann Mieczkowski, Carrie Melchisky, Beth Mineo, Brenné Shepperson, Howard Shiber Deianna Tyree, and Kimberly Warren.

Chair Ann Fisher called the meeting to order at 7:08 pm. Ann welcomed everyone to the January General Membership meeting. A **motion was made and approved** to accept the January agenda with flexibility since some members needed to leave early.

**PUBLIC COMMENT**

No public comments.

Ann **asked for and received a motion to approve** the November meeting minutes. The **motion was approved**. She then asked for and received a **motion to approve** the November and December financial reports. The **motion was approved**.

Ann introduced Maria Locuniak and Pam Bauman, education associates from the Exceptional Children Workgroup at Delaware Department of Education as the guest presenters for the evening. Maria and Pam reported on the FY 17 State Performance Plan (SPP) and Annual Performance Report (APR) indicators. The PowerPoint is attached for your reference. Bill Doolittle shared a comment on the report. He indicated the N size changes that were strongly recommended by the stake holder group were not adopted by the Department but the suggestion to use three years of data instead of two years was adopted. Bill indicated he would like for Council to review the final recommendations and DOE revisions.

**DOE REPORT**

No DOE report was given in the absence of Mary Ann Mieczkowski.

## **COMMITTEE REPORTS**

### **POLICY AND LAW**

Laura Waterland provided a brief overview of the legal memo that was previously distributed to Council electronically. Laura indicated that she was the only member of the committee present. Commentary is provided below. A **motion was made** to accept the recommendations in the legal memo provided by the Disabilities Law Program with the changes proposed by Laura. The **motion carried** with one abstention.

Commentary provided in the legal memorandum was as follows:

#### **1. Proposed DDOE Regulation 507 Regarding Student Success Planning, 22 Del. Register of Regulations 562 (January 1, 2019).**

This regulation requires school districts to create a Post-Secondary Advisement Plan (PSAP), which is a plan that outlines processes the schools district will adopt to help students learn about post-secondary education opportunities, and identify their aptitudes and interests. The regulation also requires every student in grade 8 and above to have a Student Success Plan (SSP), which is a written plan stating students' post-high school goals.

Currently, 14 Del. Admin. Code 505 requires students to have SSPs. A proposed amendment, published in the November 2018 Register of Regulations, would eliminate SSPs from Section 505. The synopsis of the proposed amendment to Section 505 stated a new regulation on the topic would be forthcoming. The Councils asked for clarification on how student post-secondary education planning would work until a new regulation was promulgated. Section 507 is that "new regulation." The amended Section 505 has not yet been adopted.

Under Section 505, an SSP fulfills two functions. First, it identifies a student's post-secondary goals, and creates "a program of study" comprised of academic courses, electives and extra-curricular activities that will prepare a student for entry into their desired career path. Next, it requires the school district to ensure the student is satisfying graduation requirements and is taking the steps necessary to meet their career goals. If there are concerns about the student failing or if they are "not on track" to meet their career goals, the SSP must identify necessary supports that the district shall provide.

Section 507 appears to remove the program of study and the identification and provision of necessary support requirements from the SSP. Section 507 defines an SSP as a "written plan which sets post-secondary goals based on a student's career interests." It states that SSPs should be developed in conjunction with student exposure to, *inter alia*, college and career information, internships, aptitude and career testing, and discussions with parental figures and school employees, and that by the student's senior year, the plan should identify "the necessary steps to transition."

Section 507 does not explicitly mandate the creation of a "program of study" nor inclusion of supports necessary to help the student reach their career goals. Removing the "program of study" and the supports requirements may make SSPs less impactful. While it is certainly helpful for students to

develop written career goals, it is likely even more valuable to assist students with creating a plan on how to achieve their written goals, and to identify and provide supports the student may need along the way. Section 507 does require an SSP to “identify the necessary steps to transition” by the student’s senior year of high school. However, a student may be more successful in their desired career path if he or she, with input and support from the school district, creates and follows a concrete plan more than one year in advance of graduation.

Section 507 does require school districts to create a PSAP, or a plan that lays out processes the school district will follow to ensure that, *inter alia*, there are “activities, supports and resources” available to allow students to gain exposure to career and college information, “such as but not limited to:...one-on-one Advisement.” Advisement is defined as “a documented process that engages students in ongoing discussion and planning with school staff to identify their personal talents and interests and plan their career goals.” It may be that students will develop a concrete plan to achieve their post-secondary goals through advisement, and it is just no longer placed in an SSP. While it seems like good policy to couple goals with plans in the same document, at least students would still be engaging in a formal career-planning process. However, if this is the case, the advisement requirement should likely be removed from subsection 4.1.2.2 to clarify that school districts are still responsible for working with students to plan their career paths, and are not just responsible for planning how the student will be exposed to opportunities to learn about career and post-secondary education opportunities and requirements. Even if students will still engage in a planning process, Section 507 still appears to eliminate the requirement that school districts identify and provide necessary supports in the event the student is failing or if they are “not on track” to meet their career goals.

Additionally, it appears school districts would no longer be required to as aggressively monitor whether a student is satisfying graduation requirements or making progress toward achieving post-secondary goals. Section 505 requires school districts to “actively monitor ... educational progress and career planning toward life goals” by holding conferences between the student and their advisor at least once every marking period. Section 505 also requires annual review and updates to the SSP, and review of the student’s transcript at the end of each school year to ensure the student is satisfying graduation requirements. Section 507 does contemplate revision of the SSP “annually as necessary” and that students should have the opportunity “have meetings with counselors, teachers, parents, guardians, care-givers at regular intervals to discuss student interests regarding careers.” However, the school district would no longer be required to review the student’s transcript at the end of the year to ensure the student is on track to graduate, nor does the regulation require conferences every marking period. While it may not be problematic to give school districts more discretion on how often they engage in the career planning process with students, Council may wish to consider recommending that an annual transcript review be included, as this requirement does not appear in other regulations. Additionally, the Councils may want to seek inclusion of a section on SSP requirements for students with IEPs. Section 505 requires SSPs to incorporate the IEP transition plan requirements in 14 DE Admin. Code 925. Section 507 would eliminate this requirement.

Finally, one minor recommendation that the Council may wish to make is to have the term “Core Course Credit” and the respective definition stricken from Section 2.0. The proposed regulation does not use that the term, therefore the definition is unnecessary.

One positive aspect of this regulation, which Council may wish to support, is the creation of the PSAP and the progress report requirement. As discussed, *supra*, school districts will have to identify processes to assist students with post-secondary education goal setting. The school districts will have to report their progress to the Delaware Department of Education annually. This oversight will hopefully ensure that students in all school districts will be getting exposure to career and post-secondary education information.

Council may wish to support this regulation, while seeking the following amendments and clarifications:

- (1) clarify that school districts will still assist students with developing a program of study or plan to clearly identify what steps a student must follow to achieve career goals, even if it is no longer placed in the SSP
- (2) amend to include a requirement that school districts identify and provide supports necessary to help a student achieve their career goals;
- (3) amend to include a transcript review requirement;
- (4) amend to include a section that requires SSPs to incorporate the IEP transition plan requirements in 14 DE Admin. Code 925;
- (5) amend to strike the definition of Core Course Credit.

## **2. Proposed DHSS Regulation Regarding Dialysis Centers, 22 Del. Register of Regulations 565 (January 1, 2019).**

The purpose of this regulation is to establish quality assurance standards for dialysis centers to implement the 2014 and 2015 changes in the law (16 *Del. C.* §122(3) (aa)). It also gives the Department of Health and Social Services (DHSS) authority to charge licensing fees to offset the costs of performing their responsibilities under the statute and regulation. This is a comprehensive regulation that aims to protect the public in obtaining dialysis services from an independent or hospital based center.

The regulation applies to dialysis centers and they are defined in both the statute and regulation as “an independent or hospital-based unit approved and licensed to furnish outpatient dialysis services (maintenance dialysis services, home dialysis training and support services or both) directly to end stage renal disease (ESRD) patient(s).”

In sum, this regulation is comprehensive and deals with all aspects of dialysis, including independent and hospital based centers, as well as home dialysis services offered by those centers. It mandates licensing requirements and gives the Department authority to impose a variety of sanctions for non-compliance with the regulation. It requires a center to have a governing body and imposes numerous duties and responsibilities on that body. Each center is required to have medical staff which includes a medical director, nurse manager, charge and staff nurses, a dietitian, social worker, patient care technicians, and water treatment system technicians. Patients or their representatives must be informed of the patient’s rights and responsibilities. An interdisciplinary team consisting of the patient or patient’s representative, nurse, social worker, dietitian, and doctor must prepare a comprehensive assessment of the patient which is then used to formulate a treatment plan. If home dialysis is provided by the center, it must be approved by the Department to provide this service and the interdisciplinary

team must oversee the training to the patient and patient caregivers. The center must also provide support services to home dialysis patients. Detailed medical records of all patients must be kept and be accessible for review by the Department. There are several patient rights measures, including a provision that requires the center to report the involuntary discharge or transfer of a patient to DHSS. This is an important safety measure. Lastly, the center must have emergency preparedness in that the dialysis machines must operate for at least four (4) hours on an alternative power source if there is a power outage.

Although some of the provisions of this regulation are onerous, the regulation deals with a medical service that is necessary for those individuals with kidney disease. This regulation should meet its intended goal of protecting dialysis patients by establishing standards and guidelines so that they receive competent medical care for a life-saving procedure. Council may wish to endorse the regulation as it comprehensively addresses this crucial outpatient service.

### **3. Proposed DMMA Regulation Regarding Chiropractic Centers, 22 Del. Register of Regulations 566 (January 1, 2019).**

The Delaware Health and Social Services/Division of Medicaid and Medical Assistance (DHSS/DMMA) proposes to amend Title XIX Medicaid State Plan and the DMMA Provider Policy Specific Manual regarding chiropractic services, specifically, to remove annual numerical limitations placed on chiropractic care visits for the purpose of treating back pain. This amendment is meant to align with the General Assembly of the State Delaware's Senate Bill 225, an Act to Amend Title 16, Title 24, Title 29, and Title 31 of the Delaware Code Relating to Insurance Coverage for the Treatment of Back Pain. The Act encourages the use of proven non-opioid methods of treating back pain by prohibiting numerical limits of chiropractic care.

Council should support the DHSS/DMMA amendment and encourage expanding access to alternative pain care treatment options.

### **4. Proposed DMMA Regulation Regarding Eligibility, 22 Del. Register of Regulations 570 (January 1, 2019).**

Federal Medicaid law contains a special protection to help individuals who have been on Supplemental Security Income (SSI) keep health insurance when they lose their SSI because they start receiving Social Security benefits on a parent's account that exceeds the SSI payment amount. Unfortunately, the Delaware Medicaid regulation that implements this provision of the federal law contained an improper provision that required the person to have received their SSI before age 22. That provision has been amended to remove the restriction, but in a way that still leaves some unintended ambiguity.

Under the previous regulation, the State required that the person have lost his or her SSI before the age of 22. That is not a requirement of the federal statute. Rather, the disability that gives rise to eligibility for Social Security benefits on parent's account has to exist before the person turned 22. The federal statute requires loss of SSI and current eligibility for Social Security benefits for a disability that began before age 22. They are required to have lost SSI, but do not need to have recovered it before age 22. There are many reasons why a disabled person may not receive SSI before age 22 that are unrelated to their disability, such as income, resource or other non-disability related eligibility criteria.

The proposed change removes the impermissible requirement that existed in the previous regulation, but is still not entirely correct. It reads: “have been receiving SSI because of disability or blindness, which began before he or she attained the age of 22.”

It is not a requirement of the federal statute that the SSI be received because of disability that began before age 22. We recommend simply dropping the words after SSI in the above sentence. The statute requires loss of SSI and current eligibility for Social Security benefits for a disability that began before age 22. There is no need to inquire regarding the basis for receipt of SSI. If a person is receiving Social Security Disability benefits on the account of a parent, by definition, that means that he or she has established to the satisfaction of the SSA that the disability began before age 22. There is simply no need for the State to be involved in this inquiry. We recommend that the Council support this change in the eligibility requirements for a vulnerable group of adults with disabilities, with the one adjustment.

#### **5. Proposed DSCYF Regulation Regarding Delacare Early Care and Education and School Aged Centers, 22 Del. Register of Regulations 574 (January 1, 2019).**

The Office of Child Care Licensing (OCCL) has re-published proposed Delacare regulations concerning the health, safety, well-being, and positive development of children who receive care in early care and education and school-age centers. This analysis will focus on amendments meant to ensure that licensed centers comply with the Americans with Disabilities Act (ADA) by meeting the needs of children with disabilities who require medication while in child care.

OCCL made a number of revisions in response to Council comments on the November 2018 version of these proposed regulations. Some of the most notable improvements include new requirements mandating that at least one staff member with a valid Administration of Medication certificate be present at all times to provide medications (Subsection 26.6), including during field trips and routine program outings (Subsection 63.1). These changes help make clear that child care centers should be prepared to administer medications on both a routine and emergency basis and during field trips. The proposed regulations could still be strengthened, however, in the ways described below:

##### **a. Written Policies on Administration of Medication and Need for Statement About Reasonable Accommodations**

Concerns still remain about how OCCL will ensure that licensees develop and consistently implement a written policy on administration of medication. Although OCCL requires policies on medication administration to be included in the parent/guardian handbook (Subsection 23.1.13), the proposed regulations do not indicate that these policies must be approved by OCCL. Nor do they provide any guidelines on what the policies in the parent/guardian handbook must convey. As was previously recommended, policies on medication administration should clearly state that the child care center will provide reasonable accommodations for children with medication needs, including medication by non-intravenous injections. New Jersey, for example, requires child care centers to inform parents and guardians that the center “will provide reasonable accommodations for the administration of medication or health care procedures to a child with special needs, if failure to administer the medication or health care procedure would jeopardize the health of the child or prevent the child from

attending the center.” Such a statement of non-discrimination is critical because parents and guardians are often unaware of their rights with regard to medications and reasonable accommodations. This lack of awareness is likely even more of a problem in Delaware because the state previously did not allow laypersons at child care centers to provide medication by injection. A formal non-discrimination statement related to medications will also promote child care centers’ compliance with federal and state anti-discrimination laws and enhance centers’ public accountability.

**b. Notice to Licensees That Administering Medication Via Injections May Be Mandatory Under State and Federal Laws**

As explained in prior comments, another major concern is that child care centers may interpret the language in Subsection 63.6 as meaning that they have complete discretion over whether or not to deliver medication by injection. We sought a subsection to Section 63.0 that clarified that medication administration – including administration via injections – must be part of the reasonable accommodations that child care facilities must make under the ADA in order to provide equal services to children with disabilities. In response, OCCL added Subsection 63.8, which states: “The administration of medication is encouraged, but not mandated pursuant to these regulations. However, if an agency, administrative body, court, or other entity responsible for enforcing Federal, State, and local laws and regulations (including but not limited to the Americans with Disabilities Act and the Delaware Equal Accommodations Law) makes a finding that the refusal of a licensee to administer medication is a violation of the law, OCCL shall take appropriate enforcement action consistent with subsection 12.5, due to licensee’s failure to comply with subsection 15.2.” The effect of the wording in Subsection 63.8 is to highlight that OCCL will not mandate the administration of medication by injection and will only take enforcement action in limited circumstances. While it is true that OCCL does not enforce the ADA or the Delaware Equal Accommodations Law (DEAL), child care facilities frequently misunderstand their obligations under these anti-discrimination laws. We therefore urge OCCL to revise Subsection 63.8 to explicitly note that medication administration may be required under state and federal laws even though it may not be mandatory under OCCL’s own regulations. This extra emphasis and clarification are especially critical because OCCL’s new regulations on administering medication by injection are a significant departure from longstanding policies. Thus, child care centers may resist modifying their own policies and practices around this issue. Yet under the ADA, child care facilities must, as a general rule, provide medication by injections when parents or guardians request them to.

**c. Comprehensive Referrals and Tracking for Complaints**

The new Subsection 12.5, referenced in the above Subsection 63.6, explains how OCCL will refer complaints relating to the laws of other governmental entities, including but not limited to the ADA and DEAL, to appropriate enforcement authorities for investigation. Subsection 12.5 also states that OCCL will request a report of the findings. Two concerns regarding this Subsection are ensuring that referrals are comprehensive and that OCCL actually follows up with the complaining party or enforcement authority for a report. Families have faced problems in the past with trying to file complaints with OCCL. For example, DLP is aware of a family who was referred by OCCL to the US Department of Justice but not the Division of Human Relations (DHR) for a case involving reasonable accommodations for a child with a disability. Because an equal accommodations complaint in Delaware must be filed within 90 days of the alleged incident, it is important that OCCL promptly refer

complaining parties to DHR when appropriate and advise parties to be mindful of deadlines. It is also unclear whether and how OCCL will receive the results of any investigation arising from a complaint to other agencies. OCCL must have a process for tracking complaints so that it can follow up on the outcome of investigations and prevent the burden from always falling on complaining parties to report back to OCCL for further enforcement activity. Moreover, for disability-related complaints, OCCL should not only refer complaining parties to the relevant enforcement authorities, but also to Community Legal Aid Society (CLASI) for advice or possible representation. As Delaware's Protection & Advocacy agency, CLASI is willing and able to help families and individuals who wish to pursue ADA and DEAL complaints.

In conclusion, while Council should endorse the proposed Delacare regulations for early care and education and school-age centers, they should also request further revisions. OCCL should require child care centers to inform parents and guardians that they will make reasonable accommodations for children with medication needs. The language in Subsection 63.8 should also be modified to more clearly warn child care centers that even if OCCL regulations do not require licensees to administer medication by injections, it may be mandatory to do so under state and federal laws. Finally, for complaints under Subsection 12.5, OCCL should promptly refer complaining parties to all appropriate agencies and develop a system for tracking complaints, as well as consider referring disability-related complaints to Community Legal Aid Society.

## **6. Proposed DELACARE Regulations Re: Family and Large Family Child Care Homes**

OCCL also proposes to amend the Delacare regulations for family and large family child care homes. These amendments are largely similar or identical to the proposed changes to the regulations for early care and education and school-age centers. CLASI recommends that Council endorse the amendments but ask for the revisions discussed in our analysis above.

## **ADULT TRANSITION SERVICES**

Cathy Cowin reported that the committee heard from Stacy Watkins from the Division of Developmental Disabilities Services (DDDS) for an update regarding the renewal of the Medicaid Lifespan Waiver program. Every five years the waiver program is required to be renewed. They are making changes that will clean up the waiver. Cathy stated that Stacy will share the documents with Council. Robert advised that the documents are marked up in red with the changes. He felt that most of the changes were good for us. Terri shared that there will be public hearings on the 14<sup>th</sup> and 15<sup>th</sup> of February. Those dates were sent out by staff. One of the changes is that the providers will now be providing the private duty nursing. Discussion ensued about the state plan amendment that is being filed regarding transition wrap around services. Laura shared that they are not using "kid language". According to law they are not allowed to discriminate according to age. Terri shared that Steve Yeatman and the kid's department formed a committee and they are working on this issue. Further discussion ensued regarding the service coordination and that it is ineffective. Terri questioned if the committee needed to have someone from ASSIST to speak to them. Cathy agreed that they could have Deanna come and speak to the committee.



## **CHILDREN AND YOUTH**

Bill Doolittle reported that the group went over their goals and discussed their progress on those goals. The group further discussed what staff support it would need to accomplish the goals set forth.

## **INFANT AND EARLY CHILDHOOD**

Chair Jennifer Pulcinella reported that the committee met with Kim Kryznowski from the Department of Education (DOE) and Christine Stoops from Parents as Teachers because she wanted to know more about what the Parents as Teachers program does. She shared that some of their objectives include personal visits, child screening, group connections and community resource networks. Primarily they work with children from birth to age 3 but they do have some funding to work with those three to five year olds that don't otherwise qualify for services. They enhance the parent's ability to use skills to access personal resources and make connections. Jennifer shared that she spoke with some professionals regarding who they refer infants to and they said Parents as Teachers. She considers them a well-regarded organization.

## **MEMBERSHIP COMMITTEE**

There was no Membership report at this time.

## **PERSONNEL COMMITTEE**

There was no report at this time.

## **AD HOC COMMITTEE REPORTS**

No Ad Hoc committee reports were given

## **OUTSIDE COMMITTEE UPDATES**

No committee updates were offered.

Bill Doolittle asked if he could address his concerns from earlier this evening during the DOE presentation. He shared that he is concerned that the parents and advocates, while being invited to participate, are not having their voices heard. He feels that they are invited so that DOE can say they participated but the Department is then primarily listening to the district input. Bill asked for a motion to send a letter to the Exceptional Children workgroup and copy Secretary Bunting about his concern. Ann asked if there was a second, there was none and after further discussion it was decided to first

request, with a letter, the new Indicator 4 targets and review that data before deciding how to proceed. Council member Jennifer Pulcinella questioned why so many of the data fields were blank on the presentation given this evening by DOE. She was reminded that Maria advised that the data was being verified and that it would be available once the report is submitted to OSEP (Office of Special Education Programs) on February 1, 2019. After discussion, member Robert Overmiller **made a motion** to send a letter to OSEP informing them that when the Department presented to us there was no data provided for most of the indicators even though we are listed as reviewing the report. The motion received a second and after a vote, it **failed to pass** with only 1 yes vote. Discussion continued regarding the lack of data provided and about what the report submitted to OSEP actually indicates that the GACEC role is. After additional discussion, a comment was made that perhaps we should address the concern first with the Exceptional Children Workgroup and the Secretary of Education before going to OSEP. Bill Doolittle **made a motion** that the letter regarding the missing data on the presentation and Council's concerns be sent to the Exceptional Children workgroup and copied to Secretary Bunting. **The motion** was approved.

### **DIRECTORS REPORT**

Ann shared that Wendy is not present due to her recent surgery. She hopes to be back full time soon.

### **FINAL REPORT FROM THE CHAIR**

Ann announced absent members and guests in attendance. Ann reminded Council that comments were needed before January 28, 2019 on the Strengthening Protections for Social Security Beneficiary's Act of 2018. DDDS will hold public hearings in New Castle County on February 14, from 9-10a.m. at the State Police Troop 2 conference room and in Sussex County on February 15 at 2pm at the Thurman Adams State Service Center in Georgetown. The Kent County meeting will take place on February 15, from 6-7pm at the State Police Troop 3 conference room in Camden. The GACEC Joint Finance Committee hearing is January 29 at 2:30p.m. Please let staff know if you plan to attend. Ann also reminded members that responses to letters could be found at the back of the room. **A motion was made and approved** to adjourn the meeting at 8:36 pm.